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THE CHALLENGE OF POPULATION CHANGES.

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As in the 1970's, the 1960's, and previous decades, the offering of comprehensive services to deaf-blind people is the perennial challenge of rehabilitation and other humanitarian services. However, much can be reported of the increased interest in the deaf-blind services within this decade and it is anticipated that the 1980's will see an ever increasing involvement of professional workers on behalf of this group.

Although this writer does not intend to leave the impression that there is no longer a need for advocacy for the general deaf-blind population, this paper will concern itself with two specific sub-groups within the total population -- the Usher's Syndrome and the Rubella deaf-blind children and adults.

A paradox seems to exist since most of us are familiar with both groups, and yet, most of us are unfamiliar with both groups.

Usher's Syndrome is a genetic disorder of congenital deafness and progressive blindness due to Retinitis Pigmentosa. Prior to the term, "Usher's Syndrome," this individual was referred to, by us, as a person with Retinitis Pigmentosa and a hearing loss. History shows that this group has been one of the more neglected and most misunderstood among the handicapped population. They have, for the most part, attended schools for the deaf, and for the most part, their eye condition was usually undetected at school despite the fact that they continued to function with diminishing skill due to an increasing loss of field vision and almost a total loss of vision at night. This visual problem did not start in their later years at school but, as a rule, started during their early teen years. School workers, unaware of this eye condition, attributed their absence from evening social events, their clumsiness, or their decreasing intellectual performance, to reasons other than defective vision.

Despite the fact that deaf people have sight as their sole input of information, very little attention has been paid to thorough ophthalmological examinations, therefore, it is not uncommon to learn that a diagnosis of Retinitis Pigmentosa may not have been made until the individual was 24 years of age, or older. At times when a diagnosis has been made, we find that some parents are not only unwilling to share this with their youngster, but forbid any constructive counseling or vocational planning with the individual. This, despite the fact that those who have Usher's Syndrome and who can intelligently express themselves state that this information should be given to the youngsters as soon as possible.

At the WORKSHOP ON USHER'S SYNDROME, held at the Helen Keller National Center in 1976, Mr. Harry J. Anderson, an Usher's Syndrome individual and, at that time,

a counselor at the School for the Deaf in Florida, stated:

"The attitude of wanting to delay telling the son or daughter why his/her eyes were being examined, or keeping him in complete ignorance of his eye condition, does more harm than good." (1)

Other Usher's Syndrome individuals have made similar statements from various platforms and have urged complete eye examinations for deaf people and the truth about their vision.

One of the first resolutions passed by the Advisory Committee of the Helen Keller National Center was to recommend that schools for the deaf, and rehabilitation workers serving the deaf, provide or encourage ophthalmological examinations for all the children and adults whom they serve. We are pleased to announce that some schools are doing this and many states are following through with such regulations, and we are hoping that those states which have not done so will follow this example in the near future.

A number of schools have recently provided appropriate eye examinations for their full school population and, as a result, a number of Usher's Syndrome students have been located where none were suspected.

Because of these examinations, the Usher's Syndrome person will be identified and known to rehabilitation services at an earlier age and, therefore, a challenge to these services. In the past, so many have literally dropped out of society because of the fact that they suffered the ignominious fate of not being counted or listed anywhere. Years later, many of these individuals were located in a state hospital, or had been referred to an agency serving the blind, where idleness, apathy, no one to communicate with for decades, was too much for the individuals, and they suddenly became violent or "too difficult to handle." As a result of this early detection, we can foresee an increasing number of Usher's Syndrome individuals requiring rehabilitation services at a much earlier age than previously.

Additional pressure upon Rehabilitation Services is brought about by the 1973 Rehabilitation Act, which provides deaf and deaf-blind students with funds for interpreters in the classroom and for study purposes. As a result of this and because these students may still maintain 20/20 central vision during their school years, an ever increasing number of Usher's Syndrome deaf individuals attain a much higher degree of education than their predecessors, and some are going on to two and four year colleges and graduate schools.

Rehabilitation services have to accept the challenge of developing or locating suitable vocational opportunities for the educational achiever who may have started school as an Usher's Syndrome deaf person, but graduates as an Usher's Syndrome deaf-blind person. Blindness, at this point, is based upon restricted fields. It must also be pointed out that neither the individual nor the counselor may have known of the progressive loss of vision at the time of entrance into college.

As if the problems already mentioned are not enough, this group is now faced with the added problem of who is to serve them. Some leaders in work for the deaf now

feel that workers for the deaf, alone, must serve this group. On the other hand, workers for the blind, who have traditionally served this group, feel that it is their responsibility once the individual falls within the classification of blind. The problems brought about by the handicap of deafness and blindness are so severe that they may actually require that both groups work together and pool their resources for the benefit of these individuals who formerly may have been bypassed by both areas of service. We are beginning to see this cooperation happen in scattered parts of the country and we do hope that it will continue. I hope that no deaf-blind person is forced to sit at home while some bureaucratic decision is being rendered as to who will provide the service.

Another phase of the changing adult population is the Rubella group who are still children, but in the very near future, will reach adulthood and whose needs are so great as to make it necessary for us all to understand these needs and to develop plans whereby these needs can be met.

As a result of the 1964-1965 Rubella epidemic, an estimated 20,000 children have become severely handicapped, about 6,000 of whom were so visually and auditorily impaired as to be classified deaf-blind as infants. Almost all of this population have one or two additional handicaps, each serious enough to constitute needs for special habilitation and/or rehabilitation service.

The problem becomes more complex when one realizes that a large number of these children have had many years of fairly intensive training in a school environment and, according to some children's workers, still function so low that fifty percent or more will require full custodial care for most of their lives. According to these workers, the other fifty percent will only function on a semi-independent level with a very small percentage possibly achieving full independence.

Millions of dollars have been spent on the "education" of this group. Hundreds of workers, both in school and out, and thousands of parents have diligently applied themselves toward them, but, and I quote Dr. Lars Guldager, the Superintendent of Oak Hill School in Connecticut:

"Despite this effort, many students graduating after as many as 18 to 20 years in such a program will be unable to take care of their own needs. The majority of the students leaving programs for deaf-blind children at the age of 21 will be in need of a life-long program to meet their needs."(2)

Although it is obvious that the total population will require a variety of strategies to meet the various goals indicated by their needs, it is also obvious that the bulk of the children of the 1964-1965 epidemic will reach age 21 at about the same time. Those of us close to the situation would prefer having them leave school at the age of 25, and why not, since almost all have been late starters.

In order to prepare for this eventuality, we have long been advocates for the classification of this population for the purpose of clarification. In 1976, in Chicago, this writer stated:

"In classifying this population, efforts should be made to learn the extent of both hearing and visual loss or, to put it on a positive note, to learn how much hearing and vision the individual has. Of course, there is serious concern about the need for some constructive planning for this group as they reach adulthood. In order to do this properly, we need to accurately identify and classify the children. Now we are at a time when we must know precisely how many children we are talking about and at what level they function.

The term "deaf-blind" for children has been a catch-all category. There was no objection to this, since it enabled many with questionable sensory disabilities to have the opportunity to receive an educational program which otherwise would have been denied to them. It is also true that many of the children functioned as deaf-blind when they were infants. The category of deaf-blind served its purpose well, but as we think and plan for the future, separation into more specific classification becomes increasingly important. The definition used by the children's program is broad and permits a wide range of visually and hearing handicapped children to fall within its framework. The children's program workers are also aware of this since many of the children are, according to them, "visually and hearing impaired"....."(3)

On occasion, I have been asked to meet children close to 20 years of age who were referred to me as deaf-blind. In a number of instances, these children have had vision beyond the classification of blind and experienced no difficulty in hearing me and it was not necessary to use any method of communication other than voice. It was quite clear to me that these children should be referred to rehabilitation agencies serving the handicapped, since I did not feel that they required the specialized services of an agency serving the deaf-blind. Furthermore, it is imperative that youngsters or adults with impaired hearing should not be with deaf people, but with others who have hearing and speech; this will enable them to utilize their own hearing to better advantage.

In California in 1978, referring to the category of deaf-blindness, I stated:

"Up until now we have only identified the sensory losses as a prelude to possible referral. Consistent with any program plan there is need to identify other characteristics. Many of the children we are concerned about have central nervous system defects, along with other physical and intellectual handicaps, in addition to the sensory losses. This has compounded the problems of educators, families and the deaf-blind children, themselves. It, therefore, becomes important to identify each child's physical and mental level of functioning, in order to avoid the concept that these children are only "deaf-blind" since, in reality, so many are "deaf-blind

multi-handicapped." Observations of this group clearly indicates that they function on several levels and apparently we will continue to see this in the foreseeable future.

There can be no doubt that needs for life-long planning must develop, but there are always these questions: "What?"; "When?"; "How?"; "For whom?"; and "How much?"; and these questions must be answered before funding can be obtained for appropriate and constructive services."⁽⁴⁾

Despite the fact that many communities offer resistance, the concept of the group or similar type homes, versus institutionalization, continues to grow. We believe that custodial care, as we have known it in the past, no longer has a place in our society, and every deaf-blind person, no matter how limited, or how advanced, should have the opportunity to an environment that promotes growth.

Some thoughts must be given toward the concept of "dependent living homes" for the very low functioning deaf-blind multi-handicapped individuals, as Dr. Guldager stated in his paper, or "rehabilitation maintenance," as Mr. Harry Spar, the Director of the Helen Keller National Center, stated in his paper. In 1972, Mr. Spar wrote:

"A special kind of residential work activity center with provision for ongoing rehabilitation maintenance may be required to best serve these deaf-blind persons."⁽⁵⁾

It is important that we understand that services should not be disrupted when these children move from childhood to adulthood. A successful legislation program whether National, State or City, can only be achieved when several interested and compassionate legislators are willing to present a bill for funding, and when a united effort on the part of the professional workers, parents, and some capable deaf-blind people, present them with meaningful information.

Assuming that age 21 is the cut-off point for school, it becomes more apparent that the educators are facing an increasingly anxious period in focusing upon ultimate placement. Appropriate placement, whether for a highly skilled deaf-blind person or a totally dependent individual, can only be determined upon an objective evaluation and observation of the total person. The fact that one person has the dexterity to work on complex assemblies does not of itself make him suitable for competitive placement, or even in a sheltered workshop. In a paper I wrote with Mr. Robert Prause, the late Placement Specialist at the Helen Keller National Center, we remarked:

"There are more jobs lost because of poor work habits and attitudes, than because of poor production performance."⁽⁶⁾

IN SUMMARY

We must be alerted to the fact that the 1980's will see an ever increasing number of the young Usher's Syndrome deaf-blind individuals requiring services immediately upon leaving school.

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An awareness of a problem does not in itself solve the problem. We, in rehabilitation, must, therefore, examine our resources and develop those areas of weaknesses. Whether or not services for the blind or the deaf, or a state specialist for the deaf-blind, will have the major responsibility for rendering service, it appears that each group will have some involvement. Because of this, it is mandatory that work for the blind continue having its staff trained in the areas of deafness and communication. Concurrently, work for the deaf should have its staff become familiar with blindness and both groups should undertake training in deaf-blindness. We, at the Helen Keller National Center, have been aware of this need and now have the one-week seminars on a more frequent basis, and more readily accept internships of various durations. We now see some workers for the blind who have had some experience with the deaf-blind population move into work for the deaf and some workers for the deaf are moving into work for the blind. This should be encouraged and continued.

Children should be registered or applications made for adult services at the earliest appropriate time with the appropriate state agency. Currently, there are many more private agencies serving the deaf-blind multi-handicapped adults than ever before, and an increasing number show evidence of accepting the challenge. There are many more workers in all fields now with some familiarity with deafness, the methods of communication and, most important of all, an interest in becoming involved.

Energetic efforts should be made at developing a financial structure for the development of homes, or any other types of appropriate facilities or programs, to insure the continuation of services many will need.

Reality time is upon us. Let us not sit and say "what shall we do?", but let us work together and decide, let us offer suggestions. Many suggestions may be rejected, but out of rejection comes alternatives and out of alternative can come success.

There is no doubt that some parents will not be entirely satisfied, some workers will not be entirely satisfied, but in the final analysis, it is the handicapped children who should be satisfied. The handicapped children deserve the best knowledge and skill we have to offer to maximize their abilities, and they must be treated with respect and dignity to maximize their feeling of self-worth.

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